



## Prostate cancer: Exploring the reasons for timing of presentation and diagnosis

There has been little research looking specifically at the reasons for the timing of when men are diagnosed with prostate cancer. This study investigated the profile of men diagnosed in Greater Glasgow over a two-year period (2008-9). This report explores the experiences of men before they were diagnosed and includes what triggered them or prevented them from presenting their symptoms to a healthcare professional. The study is based on clinical information of the patient population, a postal survey and interview data.

### Key Findings

- Older men were more likely to receive a high risk diagnosis.
- Eighty-three percent of men experienced one or more symptom. Of those men, 85% reported experiencing them for over four weeks, with 41% experiencing symptoms for over a year.
- The most common route to diagnosis for respondents was presenting to a healthcare professional with symptoms (48.3%).
- There was no statistically significant relationship between the length of time men experienced symptoms before diagnosis and clinical risk.
- Forty men (13%) approached their GP and requested a PSA test. These men were statistically significantly more likely to be from the least deprived backgrounds. They were also more likely to have low clinical risk disease, be asymptomatic and to have a friend with prostate cancer.
- Men gain knowledge of the disease from informal channels such as family or friends.
- Age and family history were not integrated into men's perceptions of their overall risk of developing prostate cancer

### Background

Prostate cancer is the most common cancer in men in the UK (Office for National Statistics, 2010) and mainly affects older men. The median age at diagnosis is 68 years (Droz et al., 2010). Recent evidence suggests that men from low socioeconomic backgrounds are significantly more likely to present with advanced prostate cancer (Greenlee and Howe, 2009) and have lower survival rates (Jeffreys et al., 2009). However, prostate cancer is seen as a 'disease of affluence' due to higher incidence rates among more affluent populations (Coleman et al., 2004).

**Delay:** Delay is mainly associated with the time from first experiencing symptoms to presenting them to a healthcare professional. There is accumulating evidence regarding the triggers and barriers to presenting with cancer symptoms and the reasons for delayed diagnosis (Corner et al., 2006; Ramirez et al., 1999). However, the specific reasons for late presentation in prostate cancer are still under-researched. Family members appear to play an important role in encouraging help-seeking behaviour (Smith et al., 2005). In addition, the existence of co-morbid conditions can impact on delay. Men may be regularly accessing primary care thus reducing their delay (Macdonald et al., 2006), alternatively they may attribute symptoms to an existing condition which masks the disease and thus increases time to presentation (Molassiotis et al., 2010).

**Risk perception:** People who feel less at risk of cancer are less likely to report promptly to a GP. Many men believe they are at low risk of prostate cancer (Fitzpatrick et al., 2009). Perceived risk is likely to be based on a knowledge of the risk factors of prostate cancer such as being older and having a family history of the disease (Johns and Houlston, 2003), as well as beliefs about the common symptoms of prostate cancer.

**Knowledge:** Studies assessing awareness and knowledge of prostate cancer have produced conflicting results with some reporting poor awareness (Fitzpatrick et al., 1998) while more recent research has found better knowledge levels (Fitzpatrick et al., 2009; Hevey et al., 2009). There is agreement, however, that the better informed someone is, the more likely they are to present sooner in the event of experiencing symptoms which match their expectations for the disease (Fitzpatrick et al., 1998; Sunny et al., 2008).

**Symptoms:** Related to knowledge, is awareness of cancer-related symptoms and symptom interpretation. There is consensus across the cancer literature that onset of vague non-specific symptoms can lead to greater delay (Molassiotis et al., 2010). This is particularly relevant in prostate cancer where symptoms generally have a slow, gradual onset. The nature of the symptoms can also prompt help-seeking behaviour, with symptoms perceived as 'more serious', e.g. bleeding, resulting in faster presentation (Macleod et al., 2009).

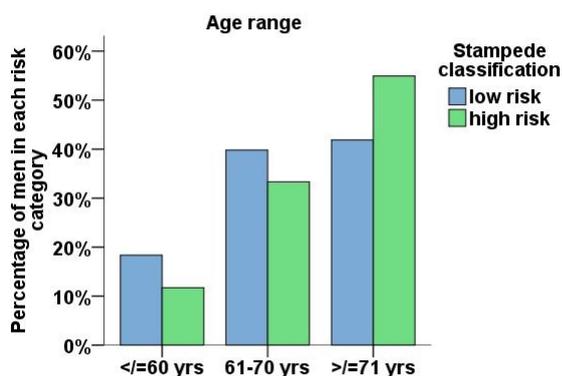
## Methods

A postal survey was sent to all men in Greater Glasgow who were diagnosed with prostate cancer in 2008/9 (N=458). The survey was returned by 320 men; a response rate of 70%. Thirty men (and their partners, where possible) were also interviewed. The survey data were analysed with statistics and the interview data were analysed to identify themes. Clinical risk was defined using criteria from the STAMPEDE trial (James et al., 2009) which classifies men as high-risk based on clinical markers from blood tests, biopsies and whole-body scans (Gleason, PSA and TNM scores).

## Findings

### Total patient population sample:

The total patient population had an average age of 69. Thirty-six percent of men were classified as having a high-risk prostate cancer. The total patient population for 2008/9 included more men from affluent areas, indicating that men from deprived backgrounds were diagnosed less frequently. Deprivation was not associated with higher clinical risk. Age, however, was associated with clinical risk, with older men more likely to receive a high-risk diagnosis.



### Symptom experience:

Eighty-three percent of men experienced one or more symptoms prior to their diagnosis. Symptoms were often related to urinating. Eighty-five percent of men who reported symptoms had experienced them for over four weeks, with 41% experiencing symptoms for over a year. There was no statistically significant relationship between the length of time men experienced symptoms before diagnosis and their clinical risk at diagnosis.

Despite many men considering their symptoms to be troublesome (57%), this did not act as a prompt for men to go to the GP. However, men who reported feeling that their symptoms were worrying (49.8%) or serious (24.5%) were more likely to seek help faster.

Men who had blood in their urine or semen were likely to perceive their symptoms as serious and to seek help quickly. They were unlikely to attribute their symptoms to normal ageing.

*I eventually was passing blood. And that's when I went to the doctor again. (Participant 38)*

Men who explained their symptoms (most commonly changes in urination) as being part of normal ageing were significantly more likely to have experienced those symptoms for over 12 months before seeking help.

*Participant 451: I would say I knew a year before that there was something wrong but I just didn't know what it was.*

*Interviewer: Oh really? What was going through your mind then?*

*Participant 451: I just, I just put it down to, well maybe it's old age or something like that.*

Men's medical history influenced how they understood their symptoms. Men who had a history of urinary tract infections presented later than men without such a medical history. Men with benign prostatic hyperplasia (a non-cancerous prostate condition) were likely to explain their symptoms with reference to this co-morbid condition.

### Routes to gaining a diagnosis:

The most common route to diagnosis was presenting to a healthcare professional with symptoms (48.3%). The majority (83%) of those who did approach a healthcare professional experienced no delay in testing/referral for testing. This is favourable compared with recent national statistics (National Cancer Intelligence Network, 2010).

*By the time I'd actually seen the doctor was when things started rolling, I won't consider there to be any delay. (Participant 91)*

A number of men (14.8%) reported attending the GP for another reason and mentioning their symptoms whilst there. This is related to the high incidence of co-morbid conditions in our sample (74%).

Forty men (13%) approached their GP and requested a PSA blood test. These men were significantly more likely to be from the most affluent backgrounds. They were also more likely to have low clinical risk disease, and to have no symptoms. These same men were significantly more likely to have a friend who had prostate cancer, and slightly more likely to have a family history of prostate cancer.

*One of my colleagues, he stays in the Ukraine, he's an Englishman, he had been diagnosed with it and he was working with me at the time. So we got talking, you know ... and he says "It would be advantageous," he says, "at your age, to just go and ask the doctor for a PSA." (Participant 157)*

Family and friends were important in prompting men to visit their GP with symptoms, with 27% of men citing this as the reason they attended primary care.

*I was telling him (friend) about the ... the trouble I had with peeing and the embarrassment etc. and he says "If you don't mind," he says, "I've got prostate cancer and it sounds like the start of prostate." He says, "That's how I was," he says, "Yeah, you're going to toilet then two minutes later you're running back to the toilet." He said, "I'd get it checked out." (Participant 77)*

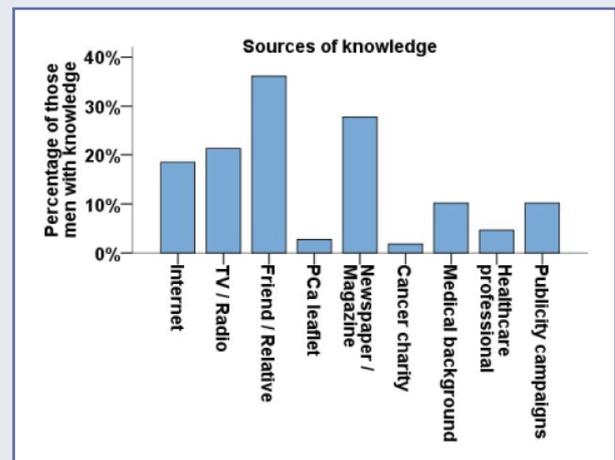
This finding was supported during interviews post-diagnosis as many men reported that they now encourage their friends/relatives to be tested.

*People I meet socially as well, most of them now have had their tests done. (Participant 14)  
Because of you? (Partner 14)  
How many men would you say that you've advised? (Interviewer)  
Oh ... certainly double figures, well, well, well into double figures. (Participant 14)  
Closer to 50 or closer to 20? (Interviewer)  
Well over 20 but maybe not as much as 50. (Participant 14)*

**Knowledge of prostate cancer:** The majority of men reported having no knowledge of prostate cancer prior to diagnosis (64%). Despite the majority of men experiencing symptoms, few sought information relating to these symptoms (21%).

*In hindsight ... I delayed because I didn't know anything about prostate problems, you know. I just assumed that what I had was something that was, that would clear up. And therefore I didn't have to push it with the doctor. (Participant 27)*

Of those who reported some knowledge of the disease, the majority (69%) knew someone with prostate cancer (PCa) before they were diagnosed. This is reflected in the finding that the most common source of knowledge was from informal channels such as family or friends (36%).



**Perceptions of risk:** The main risk factors for prostate cancer are age and family history of the disease. However, few respondents (n=21; 7%) considered themselves to be at high risk of prostate cancer. Men in the older age categories were no more likely to perceive themselves as at high risk than younger men. Those with a family history of prostate cancer (11%) were only slightly more likely to perceive themselves at high risk but there was not a significant difference.

## Policy and Practice Recommendations

Men's knowledge of risk factors for prostate cancer are low. Men are often prompted to seek tests from primary care following conversations with friends and family. This means that health promotion messages could be tailored to use relationships to drive communication and information about clinical risk factors, leading to earlier diagnosis of cancers.

## Authors

This lay summary was written by Dr Liz Forbat and Morag Place. Liz is a Senior Research Fellow and Co-Director of the Cancer Care Research Centre, and Morag is a Research Assistant. This project was funded by The Prostate Cancer Charity and is distributed by the Cancer Care Research Centre at the University of Stirling.

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